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ABSTRACT

This paper presents three case studies describing the experiences of rural families receiving early intervention (EI) services for a developmentally disabled infant/toddler. Part C of the Individuals with Disabilities Education Act (IDEA) (1997 amendments) provides funds for home-based, family-centered, transdisciplinary EI services. The case studies indicate that for rural families, the reality of home-based EI often fails to meet the goals of IDEA. The families presented here are from rural or small town settings, come from diverse backgrounds, may be struggling at low income levels, and may be reluctant to seek government support. Data interpretation focuses on early communication between infants and caregivers, the context of families as impacted by cultural and socioeconomic diversity, and client perceptions of a transdisciplinary family-focused program philosophy. The cases illustrate how family characteristics require different responses from EI providers. In addition to direct services to identified children, EI workers may need to provide social and emotional support to parents, basic assistance to families in working with medical professionals, information about and assistance with the processes for obtaining public assistance, and advice to some families with strong religious beliefs about the importance of special education services and how they can be consistent with religious beliefs. (SV)

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A LONGITUDINAL LOOK AT RURAL FAMILY OUTCOMES: FROM BIRTH TO EIGHT YEARS OLD

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This paper presents findings from an 8-year longitudinal qualitative research project involving 50 families. In-depth interviews were designed to gather information on the perceptions and experiences of parents (and other family members) of infants identified neonatally in birth crisis, or shortly thereafter, as having developmental disabilities. This paper presents case studies describing families residing in rural and small town settings. The nature of these settings necessitated the neonates undergoing medical evacuation flights to one of the two urban public hospitals in the state. This experience dramatically impacted the parents who were not transported. The unique difficulties faced by rural families, including limited availability of specialized medical and developmental services, are important factors to consider when providing special education. Recommendations for improving rural service delivery are presented based on results from intensive ongoing research on key informants who are the consumers.

This paper describes information provided by rural families including breakdowns in prenatal care that could have prevented birth crises, isolation, transportation difficulties, lack of services or trained providers. The information presented will help facilitate better communication and understanding between family members and service providers. The interview results are extremely important for professionals providing EI services, educators preparing these professionals, and policy makers who wish to improve these services.

Part C of the Individuals with Disabilities Education Act (IDEA, 1997 Amendments) recognizes the family as the strongest mediating factor in the development of very young children. The law requires that early intervention (EI) assessment and services be family directed. Research indicates that families faced with birth and developmental crises are illprepared to direct EI activities. (Winton & Baily, 1990; Haring & Lovett, 1995) Service providers need culturally sensitive strategies to inform and guide families in order to insure their full participation in the development of Individual Family Service Plans (IFSPs) (Hanson & Lynch, 1995). These plans serve as the basis for early intervention (EI) services and are designed to support the families. The underlying assumptions of EI are that: (1) families need and welcome these services and supports, (2) early interventionists know how to assist families to direct needs assessment and develop programs to meet those needs, and (3) these services enhance the development of infants and toddlers who are disabled or at-risk. Major efforts have been made, using Part C funds, to provide homebased, family centered, transdisciplinary EI services. The present research documenting implementation of this model indicates that for families in rural areas the reality of homebased EI often fails to meet the goals of IDEA.

In order to meet the intent of the law as well as to provide appropriate EI services, professionals must learn to communicate more effectively with family members. This paper will help providers better understand the contextual variables influencing how families view their identified infant or toddler and assist families to prioritize, articulate, and work towards agreed on program goals. Information to assist professionals in the early intervention process is included. The data interpretation has focused on early communication between infants and caregivers, the context of families as impacted by cultural and socioeconomic diversity, and how a transdisciplinary family focused program philosophy is perceived by recipients. The families presented here are from rural or small town settings, come from diverse

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backgrounds, may be struggling at low income levels, and reluctant to seek government support. The information obtained through this study reflects the uniqueness of all families and can help professionals to remember to honor family diversity.

The main goal of the first years of interviews was to record as accurately as possible the perceptions, feelings, and experiences of parents and family members in the EI process. The first interviews probed the issues of: (a) initial communications with professionals from a variety of disciplines; (b) transitions from hospital to home; (c) contacts from and referrals to additional services and resources; (d) realizations and adjustments to the infant's needs; (e) self perceptions and coping; and, (f) perceptions of assistance received from professionals and interpersonal (extended family, friends, neighborhood, community, other parents, or church) networks. Follow-up interviews further documented the nature of: (a) services, supports and/or resources provided to or sought by the families; (b) transitions to pre and formal school services; (c) changes in family dynamics and demographics; (d) family development as impacted by the identified child; (e) effects on siblings; (f) perceptions of special education; and (g) changes in the perception of their child with disabilities, particularly how their awareness and acceptance is influenced by school special services.

The subjects in this study included families residing in a largely rural southern plains state. Forty-seven percent of the families included in the study are from rural and small town locations. The sample reflected the ethnic diversity of the state. However, there was a small overrepresentation of families from Hispanic and Asian backgrounds compared to the entire state. In years one and two of the study, over sampling was conducted to identify a large number of families to account for attrition over the total years of the study. Families were identified primarily through mailings conducted in coordination with the EI program and other organizations, as well as through parent networking. Other papers are available describing: (a) cultural factors influencing service delivery for African American families, (b) extended family and tribally based values to consider when serving Native American families, and (c) follow along assistance needed for rural families who move to higher population centers for better jobs, school, medical, or special services. This paper is limited to the rural families who have participated in the study the longest and for whom there are written individual case studies. These families have years of interviews transcribed and coded. In addition, the triangulated data from significant others and records review from special services have been analyzed. This information has been placed in Folio VIEWS (Folio Corporation, 1993) to help in analysis and theory development.

Case studies of 3 families will be presented in order to better illustrate how individual family and child needs differ. The first family of interest is nontraditional, they are the Lighters and live outside of a small town that has a county Health Department. Shawn, the youngest child was identified for EI services by the Public Health Nurse because at close to 2 years old he had no language, difficulty walking and engaged in self-abusive tantrums. Shawn was eligible, demonstrating delays over 50% in cognitive, language, and social/emotional development, his fine and large motor skills were also poor. When the study began, Candy, Shawn's mother, was 22 years old but looked much younger despite her 3 marriages and children. His father, Dan, was considerably older, having numerous previous marriages and 8 other children. Both parents were unemployed, he due to a medical disability. The Lighter's had lost custody of all their children except Shawn and a 15 year old young man who lived with them in a small disorganized country trailerhome. They moved frequently and had no phone but the project followed them for 3 years, and Shawn had almost completed Headstart, when they had to leave the state.

Shawn and his mother benefited from homebased EI, Candy said, "I don't know what I would have done without them- came every week, helped me, worked with him." Candy credited EI with talking to her "welfare worker" to get her daycare. EI provided services for Shawn at home and in the daycare. He was almost toilet trained, had 35 words and had gained better control of his aggressive behavior in the group setting. At home, discipline and the lifestyle was somewhat erratic, he had less behavior control.

Candy was able to keep him and reported, "His brother couldn't talk at all at 5, but I was depressed- made me neglect him. Now I try to be a better parent." Candy had a seizure disorder, a history of suicide attempts and came from an alcoholic, conflicted family, but she became stable on her medication. She was trying to go to school because the public assistance requirements had changed and she feared losing Temporary Aid to Needy Families (TANF). Dan's condition didn't improve, he had been a biker and involved in drugs. He was thinking about training for a desk job. Dan had used his Vocational Rehabilitation school funds on classes in Law Enforcement, only to find out that with felony convictions and incarcerations he wasn't employable in that field.

The Lighters were a family who received consistent assistance from EI that helped support Candy emotionally and Shawn developmentally. The EI service coordinator worked with the Health and Human Services (DHS, state and federal public assistance) to keep this family together. The weekly home visits were the only way EI could be provided, as the family had inconsistent transportation. Getting Shawn in daycare and providing EI to support him provided a needed break for his family and a caring, stable environment for him.

Typically the research requests families identify a significant other for interviewing. This provides a perspective that is close to the family, but not living with them and data from interviews are triangulated. Candy could not identify a significant other, she had no friends or extended family members she trusted. Candy ask that we interview her EI service provider, Sue. A few other families identified an EI staff member as their significant other, they too lived in poverty, lacking social support. Most rural families had roots within some sense of community, often many generations had lived on the same land or all of their circle attended the same church. The Lighters did not stay connected to family or attend church, the friends that visited had business with Dan and did not relate to Candy or Shawn. Data from Sue reinforced information from the family interviews. Sue helped Candy provide for Shawn and her own medical needs. She kept in contact with the Lighter's DHS caseworker, this assisted Candy to keep her benefits and get Shawn's daycare covered. Sue and the research interviewers gained Candy's trust by listening to her nonjugdmentally and connecting her with needed resources.

The second case study involved the Rider family who still live in a rural town with one stoplight on Main Street. They do not have a county health department but do have their own school district with 2 buildings, one for elementary and one for secondary students. The Riders had an 8 year old daughter (Amy) and a son Trevor, who was born in a medical crisis. Trevor had a cleft palete and lip as well as neurological anomolies including no corpus callosum (this lies between the two hemispheres and provides communication between them). They live in a small, older house which is well maintained and brightly painted. Trevor was medflighted at birth, leaving his mother Tina recovering from a cesarean in a small regional hospital. Larry, his father and members of both parent's families commuted between hospitals. When Tina was able to visit Trevor, she had a very difficult time forcing herself to go to the hospital. Her own mother, who also had a cleft, abandoned her at a young age. Memories of her mother made it difficult for her to look at Trevor. Tina had nursed Amy and enjoyed a close bonded relationship with her. She had difficulty bonding with Trevor, who had feeding problems and guilt feelings about her perceived inability to mother. These negative feelings continued through his first surgery and became unacceptable to Tina when she finally understood his diagnosis (he was a year old). Up to Trevor's first birthday, Tina refused EI services, she didn't think she needed them. When he wasn't sitting up at a year, EI was invited back into the home.

The Rider family received extended family, church and community social as well as financial support. While Trevor was still hospitalized, the church held a raffle and earned over $3,000 to help with his medical expenses. Although Larry had his own business, meeting most familiy needs, their insurance didn't cover Trevor's dental care or some of the cosmetic surgery he would require. The Rider's were active members of their church, holding deep, fundamental Christian beliefs. This provided comfort, but

Tina experienced extreme guilt due to Trevor's condition. She told interviewers that each time another piece of information about Trevor was provided, she felt the devil was testing her. The Riders also believed that prayer would cure Trevor, this contributed to the delay in accepting EI services. Once EI provided homebased services, a physical therapist showed Tina how to support him towards sitting, reaching and finally pulling up to standing, she was amazed at his progress. Each member of the family worked with Trevor daily to help him achieve motor, language and play skills. This child and family did everything that EI providers suggested and by the time Trevor was 3, he had progressed so much he was not eligible for special education public school services.

The school district did not provide preschool services. They were members of a cooperative and bussed students with severe disabilities to a school only for students with disabilities out of district. This could have been a situation where the success of EI is negated by lack of follow through. However, Tina was determined to learn everything she could to help her son. She became an instructional assistant for special education at the local elementary school and started taking classes towards her teaching certification. Tina made tremendous growth, from being unable to look at Trevor, to working with him daily and developing a career surrounding him. He now attends the elementary school with special education support in regular classes.

The third family for discussion are the Patels, an immigrant family in which two Asian brothers married two American sisters. The Patels live on acreage, down a dirt road off of a rural route. They live in a one room house with a beautiful view and no neighbors. Tara and Ravi had been married ten years before the long anticipated birth of Isadora. Ravi was a media specialist who commuted to work, Tara sometimes worked but had serious health problems. Isadora was not breathing at birth and medflighted to an urban NICU. Tara's mother assisted with travel between hospitals and communication with doctors, but the family had difficulty understanding what was wrong with Isadora. This period of crisis was particularly difficult for Tara because she couldn't see her daughter for a week. Isadora was in a coma for 3 weeks, finally a diagnosis of cytomegalic inclusion disease was made. This is a neonatal condition caused by the cytomegalovirus (CMV) and can be fatal. Isadora contracted CMV inutero causing deaf-blindness and microcephally. Once Tara was able to establish that the only reason Isadora was still hospitalized was for oral tube feeding, she learned the procedure and took her home.

The doctors wanted to surgically install a gastrostomy (G) tube for feeding Isadora but Tara refused. The Patel's received homebased EI and this helped her fade the oral tube feeding and teach Isadora to take a bottle. As Isadora aged, Tara has taught her to eat all varieties of food and has maintained her weight so a G tube isn't necessary. Isadora is multiply and severely disabled, Tara devotes her life to caring for this child. During the first 3 years of Isadora's life, Tara reported satisfaction with EI services. The IFSP required that Isadora receive direct service from 3 therapists and a Resource Coordinator. However, services were sporadic and many weeks went by with no home visits. Due to the CVM diagnosis, there were constant changes in EI personnel because most of the staff were young women planning pregnancy who didn't want to risk exposure.

Isadora is now bussed to a special education only school. Tara, who initially feared her daughter going to school, now thinks it superior to EI because it is so much more intense. On reflection, she realizes that she did not get very much EI service and that she was the one who mainly worked with Isadora. Tara said, "They say you have a choice, but you really don't have one because you don't have a clue." The most important decision Tara made was to feed Isadora herself. This child has deafblindness and taste became a critical way for her to communicate preferences. EI was able to help with positioning and feeding. Tara said the most important thing to her was that Isadora be aware of her surroundings. EI never suggested they work on a communication program for Isadora or referred her to services for deafblind infants. Even if EI had been able to provide a hour a week of homebased services, that is not enough to dramatically impact the development of a child with Isadora's level of disabilities.

The case studies illustrate how family characteristics require different responses from EI providers. In some cases EI must provide social and emotional support to parents as well as direct service to identified children. In each case, careful listening, active perception and nonjudgemental communication skills are required. EI may also need to provide basic assistance to families in working with medical professionals. This assistance may take the form of helping families meet medical appointments or being with the family when they talk with medical personnel to help the family members understand information and to assist them to follow up on medical advice.

EI providers must be aware that they will be working in home environments that may seem inadequate from a middle class suburban perspective. One half of the families in the study receive support from the DHS. EI providers should recognize that families may not receive and may not want the governmental supports for which they are eligible. Many of the eligible rural families did not receive public assistance, some families are too proud to accept help. The EI providers may wish to help the families question this perception in a sensitive manner. Resource Coordinators need to be familiar with the required paperwork, policies, and processes for obtaining public assistance. They need tactful strategies for acquiring information, explaining the various avenues for assistance, and being able to help parents through the lengthy delays they may encounter in the process of getting a Medical Card or Social Security Income for the identified child. Also, EI providers must be prepared to assist disorganized families to understand the required documentation and how to maintain that information in order to access and sustain government support. Families may need to be supplied with organizing materials such as notebooks, resource manuals, calendars, day planners, folders, etc. to keep documents and information organized. It is also important for EI providers to understand and anticipate the diversity of family abilities in accessing assistance.

Some families with fundamental religious beliefs have chosen to home-school their children. They may concentrate on prayers for healing rather than working on adaptive responses and the development of supports for their child's needs. This interrupts school transition and can deny children special services and socialization outside of the home. It is important for EI providers to help these parents realize that the provision of special services is important and can be consistent with their personal beliefs.

The researchers are now following seven and eight year old children who were identified as having developmental disabilities in 1990. The longitudinal nature of the study has helped to raise and explore some interesting issues. For example, some young children who received early intervention have progressed so well that they were not eligible for public school services when they became three years old. The development of these and other children who were, but are no longer, eligible for special services should be monitored to ensure that possible future developmental delays are detected early or prevented. The probability of regression with underserved preschoolers with disabilities is substantial and the longitudinal data set documents the serious nature of these problems.

Some local education agencies do not have preschool programs. The state in which this study was conducted does not serve three year old children in Headstart programs and prefers to target children with mild disabilities to meet the 10% mandate for serving students with disabilities. If a school has a preschool and will accept the identified child, the probability is high that the program will be self-contained and only for children with disabilities. In these situations, families do not become familiar with more inclusionary models of service delivery and may not value inclusive programs as the child ages.

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